



## Individualized Cancer Care

A study examining women's breast cancer treatment experiences and decision making

**Conducted by:** Emory University, Keck School of Medicine at the University of Southern California, and the University of Michigan

**Return to:**

**Questions?**

This study is funded by a grant from the National Cancer Institute and has been approved by the Institutional Review Boards of Emory University, the University of Southern California, and the University of Michigan.

## General Instructions

PLEASE READ THESE INSTRUCTIONS CAREFULLY

- Answer each question as best you can. Please do not leave any blank. However, if you feel that you do not wish to answer a question, please write 'skip' next to it and continue on to the next question.

- Put an **x** or fill in the circle **●** next to your answer.

**Example:**    ☒ Yes    or    ☐ Yes

- Please erase or cross your answer out completely if you want to change your answer.

**Example:**    ~~☐ Yes~~

- Mark only one response for each question unless other instructions are given, such as “**Mark ALL that apply**”.

- Please follow any instructions or arrows that direct you to the next question.

**Example:**    ☒ No    **————→ Please go to F9 on the next page.**

- If you mark an answer with a line after it, please write the specific information on the line.

**Example:**    ☐ Other (please explain):    It was less than one week.

**Please be reminded that your responses to this survey are confidential and will not be shared with your doctors.**

## Section A: How Are You Doing?

In general...	Excellent	Very good	Good	Fair	Poor
A1. Would you say your health is ...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A2. Would you say your quality of life is ...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A3. How would you rate your physical health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A4. How would you rate your mental health, including your mood and your ability to think?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A5. How would you rate your satisfaction with your social activities and relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Excellent	Very good	Good	Fair	Poor
A6. <b>In general</b> , please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Completely	Mostly	Moderately	A little	Not at all
A7. To what extent are you able to carry out your everyday physical activities, such as walking, climbing stairs, carrying groceries, or moving a chair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Often	Always
A8. <b>In the past 7 days</b> , how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

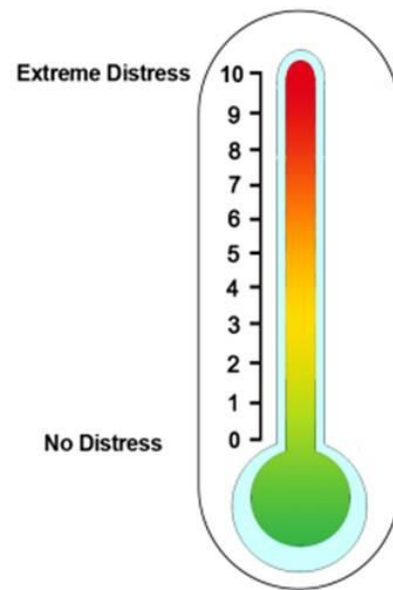
	None	Mild	Moderate	Severe	Very severe
A9. How would you rate your fatigue <b>on average</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No pain										Worst imaginable pain
A10. How would you rate your pain <b>on average</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A11. How are you doing overall?

Please look at the thermometer to the right and write in the number from 0-10 on the line below that best describes how much distress you have been experiencing **in the past 7 days, including today:**

\_\_\_\_\_ (0-10)



Now, we would like to know more about how you have been feeling **in the past 7 days.**

During the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
A12. I feel fatigued.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A13. I have trouble starting things because I am tired.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A14. How run-down did you feel on average?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A15. How fatigued were you on average?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past 7 days...	Never	Rarely	Sometimes	Often	Always
A16. I felt fearful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A17. I found it hard to focus on anything other than my anxiety.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A18. My worries overwhelmed me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A19. I felt uneasy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A20. I felt depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A21. **In the past 7 days,** I have been bothered by side effects of treatment.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	A little bit	Somewhat	Quite a bit	Very much

A22. Please tell us whether you have ever been told by a doctor that you had any of the following health conditions:

	Yes	No
a. Chronic bronchitis or emphysema	<input type="radio"/>	<input type="radio"/>
b. Heart disease, such as coronary artery disease or congestive heart failure	<input type="radio"/>	<input type="radio"/>
c. Diabetes	<input type="radio"/>	<input type="radio"/>
d. Blood clots in the legs or the lung	<input type="radio"/>	<input type="radio"/>
e. Connective tissue disease, such as lupus or scleroderma	<input type="radio"/>	<input type="radio"/>
f. Stroke	<input type="radio"/>	<input type="radio"/>
g. Depression	<input type="radio"/>	<input type="radio"/>

## **Section B: Testing of Your Cancer**

B1. What was the date when you were first diagnosed with breast cancer? \_\_\_\_\_ / \_\_\_\_\_  
month year

Next, please tell us about the tests you received to evaluate your breast cancer.

### **Biopsy**

B2. A biopsy is a procedure where tissue or cells are taken from the breast to test for cancer. On which breast did you have a biopsy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Left	Right	Both

B3. When you first had your biopsy or biopsies, were you told you had cancer in **both breasts**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

### **Imaging Tests**

B4. How involved were you in deciding whether or not you had imaging tests – such as CT scans, breast MRI, or bone scans – to find out if cancer had spread to other places in your body?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

## **Breast MRI**

Next, we would like to ask you about a Breast MRI (magnetic resonance imaging test). A Breast MRI is a scan in which a patient lies down and is placed inside a machine that uses a powerful magnet to take pictures of the breast. The machine is very noisy. Patients are asked before the test about any metal in the body.

B5. **After diagnosis**, did you have a Breast MRI to evaluate the extent of your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

## **BRCA Genetic Tests**

The next questions refer to genetic testing for cancer risk. These tests – often called BRCA tests or multi-gene panel tests – look for gene mutations or changes to see if women and their families have a greater risk of developing breast cancer in the future.

B6. Did a doctor or other health professional talk with you about having a genetic test for breast cancer risk?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

B7. Did you have a counseling session with a genetic counseling expert – that is, an appointment where the whole discussion is about genetic risk for breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

B8. How much did you want to have a genetic test to tell you the risk of you or your family developing new cancers in the future?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	A little bit	Somewhat	Quite a bit	Very much

B9. Has a family member ever had a genetic test to determine if they carry a gene mutation (or change) for breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

B10. Does any member of your family have a gene mutation that increases the risk of breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

B11. BRCA genetic panel tests are ordered by a doctor and can be done with either a blood test or a saliva test where you rinse your mouth with mouthwash and spit into a tube.

Have you **ever** had a blood or saliva genetic test for breast cancer risk that was ordered by a doctor?

Please mark “yes”, “no”, or “don’t know” and then follow the arrow.

☐ Yes

Please answer questions ‘a – c’ below

a. Why did you get tested?

Please mark **ALL** that apply.

- ☐ My doctor thought I should
- ☐ I wanted to get more information about my own health
- ☐ I wanted to get more information for my family members
- ☐ Because of my family history
- ☐ My family wanted me to be tested
- ☐ Other (please explain): \_\_\_\_\_

-----

b. When did you have the test?

- ☐ Before I was diagnosed with breast cancer
- ☐ After I was diagnosed with breast cancer

c. What was the result? Please mark **ONE**.

- ☐ I did not have any mutations in the gene tests
- ☐ I had a mutation in a gene that increases the risk of breast cancer (BRCA1 or BRCA2)
- ☐ A gene mutation was found, but not one that has been shown to increase the risk of breast cancer
- ☐ I don’t know the results
- ☐ Other (please explain): \_\_\_\_\_

-----

Please continue to B12 on the next page

☐ No ☐ Don’t know

Please answer question ‘d’ below

d. Why haven’t you had a genetic test for breast cancer risk?

Please mark **ALL** that apply.

- ☐ I don’t know if I’ve had a genetic test
- ☐ My doctor didn’t recommend it
- ☐ I didn’t want it
- ☐ My family didn’t want me to get it
- ☐ It was too expensive
- ☐ Other (please explain): \_\_\_\_\_

-----

Please continue to B12  
on the next page

## Tumor Tests

Some patients have their cancer tumor sent for additional testing. Examples of this type of test are **Oncotype DX®** and **Mammaprint/Symphony®**.



B12. Was your cancer tumor sent for the Oncotype DX or Mammaprint/Symphony test?

<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Don't know
------------------------------	-----------------------------	-------------------------------------

↓

→ Please go to C1 at the top of the next page

B13. What were the results of the Oncotype DX or Mammaprint test for your tumor?

<input type="radio"/> Low risk	<input type="radio"/> Intermediate risk	<input type="radio"/> High risk	<input type="radio"/> I don't remember
-----------------------------------	--	------------------------------------	---

B14. How helpful was the Oncotype DX or Mammaprint test in making a decision about whether or not to get **chemotherapy**?

<input type="radio"/> Not at all helpful	<input type="radio"/> A little helpful	<input type="radio"/> Somewhat helpful	<input type="radio"/> Very helpful	<input type="radio"/> Extremely helpful
---	---	---	---------------------------------------	--

B15. Did the Oncotype DX or Mammaprint test change your mind about whether or not to get **chemotherapy**?

<input type="radio"/> Made me <u>much less</u> interested in chemotherapy	<input type="radio"/> Made me <u>less</u> interested in chemotherapy	<input type="radio"/> Did not change my mind	<input type="radio"/> Made me <u>more</u> interested in chemotherapy	<input type="radio"/> Made me <u>much more</u> interested in chemotherapy
--	---	---	---	--

B16. How helpful was the Oncotype DX or Mammaprint test in making a decision about whether or not to get **radiation therapy**?

<input type="radio"/> Not at all helpful	<input type="radio"/> A little helpful	<input type="radio"/> Somewhat helpful	<input type="radio"/> Very helpful	<input type="radio"/> Extremely helpful
---	---	---	---------------------------------------	--

B17. Did the Oncotype DX or Mammaprint test change your mind about whether or not to get **radiation therapy**?

<input type="radio"/> Made me <u>much less</u> interested in radiation therapy	<input type="radio"/> Made me <u>less</u> interested in radiation therapy	<input type="radio"/> Did not change my mind	<input type="radio"/> Made me <u>more</u> interested in radiation therapy	<input type="radio"/> Made me <u>much more</u> interested in radiation therapy
---	--	---	--	---

Please continue to C1 on the next page



## Section C: Your Treatments

C1. What types of doctors did you consult with about your treatment decisions before your surgery?  
**Please mark ALL that apply.**

- ☐ Surgeon (a doctor who performs breast surgery)
- ☐ Radiation oncologist (a doctor who specializes in radiation treatment)
- ☐ Medical oncologist (a doctor who specializes in chemotherapy)
- ☐ Plastic surgeon (a doctor who performs breast reconstruction)
- ☐ Primary care provider (a doctor, physician assistant, or nurse practitioner who sees you for common problems or standard checkups)

### Surgery

C2. What was the first surgery that you had to remove your breast cancer after the biopsy test?

- ☐ I did not have any surgery after the biopsy
- ☐ I had a mastectomy (removal of the entire breast)
- ☐ I had a lumpectomy (removal of the cancer and some surrounding tissue)

**Please go to C3 at the top of the next page**

a. Did you have a second lumpectomy to remove more breast tissue from the same breast?

- ☐ Yes – I had another lumpectomy to remove more breast tissue from the same breast
- ☐ No – I only had one lumpectomy

b. Did you have a mastectomy later, on the same breast?

- ☐ Yes – I had a mastectomy after my lumpectomy
- ☐ No – I did not have a mastectomy

c. How strongly did your doctor recommend that you have a mastectomy after your initial lumpectomy?

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Very strongly         | Strongly              | Moderately            | Weakly                | Not at all            |

d. How strongly did you request to have a mastectomy after your initial lumpectomy?

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Very strongly         | Strongly              | Moderately            | Weakly                | Not at all            |

**Please continue to C3 on the next page**

C3. What kind of mastectomy did you have?

- ☐ I did not have a mastectomy
- ☐ Mastectomy only – no reconstruction
- ☐ Mastectomy with reconstruction and I kept my own nipple, called a nipple sparing or nipple saving mastectomy
- ☐ Mastectomy with reconstruction and my original nipple was removed

C4. What type of breast reconstruction did you have?

- ☐ I have not had any breast reconstruction surgery
- ☐ A DIEP flap, TRAM flap, or latissimus dorsi flap (uses your own tissue from the abdomen or back)
- ☐ An implant (silicone or saline)
- ☐ Other (please explain): \_\_\_\_\_

C5. Did you have a mastectomy on **both breasts**? ☐ Yes ☐ No

Please continue to C6

Please go to C7 at the top of the next page

C6. How important were the following factors in your decision to have a mastectomy on **both breasts**?

	Not at all important	A little important	Somewhat important	Quite important	Very important
a. My age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Having cancer in <b>both</b> of my breasts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Having a biopsy that was pre-cancerous in my " <b>other</b> " breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Having a positive BRCA 1 or 2 genetic test result	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Having a family history of breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Wanting reconstruction to best match my breasts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Wanting reconstruction to change the size of my breasts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Wanting peace of mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C7. For each of the items below, **please mark ONE response** on each line that best describes your opinion.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I am satisfied with the decision about what kind of surgery to have.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I wish I had given more consideration to other surgical treatment options.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I would like to have had more information when the decision about surgery was made.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I would like to have participated more in making the decision about what kind of surgery to have.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I am satisfied with the amount of time I had to make decisions about what kind of surgery to have.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C8. Breast cancer sometimes spreads to the lymph nodes under the armpit. Which of the following best describes what was done to the lymph nodes under your armpit? **Please mark ONE.**

- ☐ I did not have any lymph nodes removed
- ☐ I had a sentinel node biopsy ONLY – where a radioactive material or blue dye was injected into the breast and only one or a few lymph nodes in the armpit were removed
- ☐ I had a complete axillary dissection – where all or most of the lymph nodes were removed



A. How were all or most of the lymph nodes removed? **Please mark ONE.**

- ☐ I had a needle biopsy before my surgery that showed cancer in the lymph nodes under the armpit, so all of the lymph nodes were taken out later during my surgery
- ☐ I had a single operation in which my sentinel nodes were tested and found to have cancer, so all of the lymph nodes were taken out at that time
- ☐ I had a single operation in which all of my lymph nodes were removed – no needle biopsy or sentinel node testing was done
- ☐ My sentinel nodes were found to have cancer during a first operation, so I had a second, separate operation to remove all of the lymph nodes
- ☐ I'm not sure how the lymph nodes were removed

- ☐ I don't know

C9. **At the time of your breast cancer diagnosis**, how much time did it take you to get from your home to the nearest hospital?

<input type="radio"/> Less than 15 minutes	<input type="radio"/> 31 to 60 minutes	<input type="radio"/> I don't know
<input type="radio"/> 15 to 30 minutes	<input type="radio"/> More than 60 minutes	

C10. **At the time of your breast cancer diagnosis**, how much time did it or would it have taken you to get from your home to the nearest radiation treatment facility? (*Please answer even if you did not have radiation therapy.*)

<input type="radio"/> Less than 15 minutes	<input type="radio"/> 31 to 60 minutes	<input type="radio"/> I don't know
<input type="radio"/> 15 to 30 minutes	<input type="radio"/> More than 60 minutes	

C11. Partial breast irradiation (PBI) involves having radiation to only the part of the breast where the tumor was removed, rather than the whole breast. For each of the items below, **please mark ONE response** on each line that best describes your experience.

Did any doctor tell you that partial breast irradiation (PBI)...

	Yes	No	Don't know
a. Was an option for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Works as well as whole breast irradiation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Is still being studied?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. May lead to a worse cosmetic result?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## **Radiation Therapy**

C12. Did you have radiation therapy to treat your breast cancer?

**Please mark “yes”, “no”, or “not yet” and then follow the arrow.**

☐ Yes

**Please answer questions ‘a – d’ below**

a. How many weeks of radiation treatments did you have?

☐ 1 week

☐ 2-4 weeks

☐ 5 weeks

☐ 6 or more weeks

☐ Other (please explain): \_\_\_\_\_

b. How was your radiation treatment given?

**Please mark ALL that apply.**

☐ Using beams from outside my body

☐ Using a balloon placed inside my breast

☐ Using needles placed into my breast

\_\_\_\_\_

☐ I don’t know how my radiation treatment was given

c. Which of the following areas were treated with radiation?

**Please mark ALL that apply.**

☐ My whole breast

☐ Only the part of the breast where my tumor was

☐ The chest wall, after my mastectomy

☐ The lymph node areas

d. Did you have ALL of the radiation treatments that your doctor told you to have?

☐ Yes

☐ No

☐ I’m still receiving treatment

**Please continue to C13 on the next page**

☐ No      ☐ Not Yet

**Please answer question ‘e’ below**

**Please go to C13 on the next page**

e. Why didn’t you, or don’t you, plan to have radiation therapy?

**Please mark ALL that apply.**

☐ My doctor(s) did not discuss it with me

☐ My doctor(s) said I didn’t need it

☐ My doctor(s) left it up to me and I chose not to

☐ I was worried about side effects or complications

☐ I was worried about the cost

☐ It would have been too much of a burden on me or my family

☐ Other (please explain): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Please continue to C13 on the next page**

### **Chemotherapy**

C13. Chemotherapy is a treatment where medicine is given into a vein to try to kill any cancer cells in the body that may remain after surgery.

Did you or are you going to have chemotherapy to treat your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes – I am finished with chemotherapy	Yes – I am still getting chemotherapy	Yes – I plan to get chemotherapy but haven't started yet	No

### **Hormonal Therapy**

C14. Hormonal therapy helps block estrogen from getting to cancer cells that may remain in the body. Hormonal therapy is sometimes called “anti-estrogen therapy” or “endocrine therapy.” Examples include **tamoxifen**, **anastrozole** or Arimidex, **letrozole** or Femara, and **exemestane** or Aromasin.

Have you or are you going to be taking any of these medications? **Please mark ONE.**

- ☐ Yes, I currently take one of these medications
- ☐ Yes, I took one of these medications before but no longer take it
- ☐ Yes, I plan to take one of these medications in the future but haven't started yet
- ☐ No, I am not taking any of these medications right now and I am unsure whether or not I should start
- ☐ No, I have no plans to take any of these medications

### **Clinical Trial Participation**

Clinical trials are research studies that involve patients. They are designed to test the safety and effectiveness of new treatments and to compare new treatments with the standard care that people currently get.

C15. Have you ever been invited to participate in a clinical trial for treatment of your cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

C16. Have you ever participated in a clinical trial for treatment of your cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

## Side Effects During Treatment

C17. During treatment – **including surgery, radiation, and chemotherapy** – please tell us how severe each of these side effects was at its worst.

At its worst, what was the severity of your...	None	Mild	Moderate	Severe	Very severe
a. Nausea and vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Loose or watery stools or diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Constipation or hard stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Arm swelling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Breast skin irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Feelings of sadness or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C18. Next, we would like to know if you got help from your health care team to deal with any side effects of treatment – even one time. **Please mark ALL that apply on each row.**

	I did not have or seek help for this problem	I called or emailed for help	I discussed it at a routine clinic visit	I went for an <u>unscheduled</u> clinic visit	I went to the emergency room or hospital
a. Nausea and vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Loose or watery stools or diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Constipation or hard stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Arm swelling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Breast skin irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Feelings of sadness or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section D: Decision Making

D1. In **general**, please tell us how often you have these thoughts and feelings when you make decisions.

	Never	Rarely	Sometimes	Often	Always
a. I worry about making a bad decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I struggle to decide what the right decision is.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Once I make a decision, I don't look back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I get angry at myself when I have made a bad decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I worry a lot about the outcomes of my decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I forgive myself when I make a bad decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now we would like to understand how you decided what treatments to receive for your breast cancer.

D2. Did you spend more time thinking about your instincts and feelings or weighing the pros and cons?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Almost all of my time thinking about my instincts and feelings	More of my time thinking about my instincts and feelings	More of my time weighing the pros and cons	Almost all of my time weighing the pros and cons

D3. Were you more intuitive or more rational in your thinking?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Always intuitive	Mostly intuitive	Mostly rational	Always rational

D4. Did you really think things through or did you go with your first instinct?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Always thought things through	Usually thought things through	Usually went with my first instinct	Always went with my first instinct

D5. Did you spend a lot of time reviewing the details or did you make decisions quickly?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Always spent a lot of time reviewing the details	Usually spent a lot of time reviewing the details	Usually made decisions quickly	Always made decisions quickly

D6. Did you do what seemed most logical or did you just follow your heart?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Always did what seemed most logical	Usually did what seemed most logical	Usually followed my heart	Always followed my heart



D7. When making decisions about how to treat my breast cancer...

	Not at all	A little	Somewhat	Quite a bit	A lot
a. I weighed the pros and cons of all the treatment options.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I feel like I really thought through all the issues important to the treatment decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I talked with others – family or friends – before making treatment decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I talked with other breast cancer patients before making treatment decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I spent time thinking about all of the treatment options.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D8. **When decisions were being made about your treatments**, how important was it to you that your treatments...

	Not at all important	A little important	Somewhat important	Quite important	Very important
a. Reduced the need for more surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Allowed you to avoid side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Allowed you to avoid exposure to radiation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Required fewer trips back and forth for treatment visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Did not make you feel bad about your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Kept you from worrying about the cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Allowed you to feel feminine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Were the most extensive possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When decisions were being made about your treatments, how important was it to you that your treatments...

	Not at all important	A little important	Somewhat important	Quite important	Very important
i. Were the least extensive possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Allowed you to keep your original breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Were what your partner/family wanted you to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Were what your doctor wanted you to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. Were the same treatments that other women you know have received	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. Were the newest, most advanced treatments available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o. Had the shortest recovery time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p. Did not require you to spend a lot of your own money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

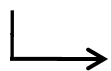
### Surgery decisions

D9. When did you make a decision about your initial surgical treatment?

- ☐ Before my first visit with a surgeon
- ☐ After my first visit with a surgeon
- ☐ After two or more visits

D10. Did you see a second surgeon for an opinion about your surgery treatment options?

☐ Yes



a. Did that second surgeon perform your breast surgery?

☐ Yes

☐ No

☐ No

D11. How strongly did the surgeons you consulted for breast cancer recommend one option over the other for your initial surgery?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly recommended <u>lumpectomy</u>	Weakly recommended <u>lumpectomy</u>	Did not recommend one surgery option over the other	Weakly recommended <u>mastectomy</u>	Strongly recommended <u>mastectomy</u>

D12. How strongly did you consider having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very strongly	Strongly	Moderately	Weakly	Not at all

D13. How strongly did the surgeons you consulted for breast cancer recommend having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly recommended it	Weakly recommended it	Did not make a recommendation – left it up to me	Weakly recommended <u>against</u> it	Strongly recommended <u>against</u> it

D14. My surgeons told me that having a mastectomy on my “other” breast – the breast without cancer – would:

	Yes	No	Not discussed
a. Give me a better chance of surviving the breast cancer I already have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Reduce the chances of the breast cancer I already have coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Reduce the chances of developing a new cancer in my “other” breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Improve the cosmetic outcome of my surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Make my recovery from the surgery take longer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D15. For each of the items below, **please mark ONE response** on each line that best describes your experience.

**Since your breast cancer diagnosis**, have you been told by a doctor that...

	Yes	No
a. Breast reconstruction is an option for women who have a mastectomy?	<input type="radio"/>	<input type="radio"/>
b. Patients who need radiation after mastectomy shouldn't get breast reconstruction until <u>after</u> the radiation is complete?	<input type="radio"/>	<input type="radio"/>
c. Your insurance should cover most of the cost of breast reconstruction?	<input type="radio"/>	<input type="radio"/>

D16. Have you talked to a plastic surgeon about breast reconstruction?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Not yet, but I plan to

### **Chemotherapy decisions**

D17. When did you decide about whether or not to have chemotherapy?

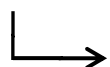
- ☐ Before I consulted with a medical oncologist
- ☐ After my first visit with a medical oncologist
- ☐ After two or more visits
- 
- ☐ I did not consult with a medical oncologist

D18. How strongly did the first medical oncologist you consulted recommend chemotherapy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very strongly recommended it	Weakly recommended it	Left it up to me	Weakly recommended <u>against</u> it	Very strongly recommended <u>against</u> it	I did not consult with a medical oncologist

D19. Did you see a second medical oncologist for an opinion about chemotherapy?

☐ Yes



a. Did that second medical oncologist treat you with chemotherapy?

☐ Yes ☐ No

☐ No

## Section E: How You Feel About Your Decisions

Please tell us how you feel about the decisions that were made for your breast cancer treatment. If your doctor did not offer you the test or treatment that is listed, please select N/A for “Not applicable.”

E1. Please rate the **amount of information** you had when the following decisions were made:

	Not enough		Just right		Too much	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E2. Please rate the **amount of involvement** you had to make the following decisions:

	Not enough		Just right		Too much	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E3. Please rate the **amount of time** you had to make the following decisions:

	Not enough		Just right		Too much	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E4. How **satisfied** are you with the decision about...

	Not at all satisfied	A little satisfied	Somewhat satisfied	Quite satisfied	Totally satisfied	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E5. How much do you **regret** the decision about...

	No regret	A little regret	Some regret	Quite a bit of regret	Total regret	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much do you **regret** the decision about...

	No regret	A little regret	Some regret	Quite a bit of regret	Total regret	N/A
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section F: Questions about Breast Cancer

Please answer the following questions about the tests and treatments for breast cancer.

### Tests

F1. Having a **breast MRI** before surgery increases the chances of...

	Yes	No	Don't know
a. Surviving breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Having a mastectomy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The cancer being completely removed during the first surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Needing another biopsy of one or both breasts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

F2. What is the purpose of getting **BRCA genetic testing** after a diagnosis of breast cancer?

	Yes	No	Don't know
a. To help women decide how to treat their breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. To help determine a woman's risk for developing a new breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. To help women who are found to be "high risk" consider ways to prevent further cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. To help a woman know if her family members may be at risk for getting breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

F3. Out of 100 women diagnosed with breast cancer, how many have a mutation of the breast cancer genes BRCA 1 or 2?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Few (0-10 women)	Some (11-25 women)	Quite a few (26-50 women)	Many (51-75 women)	Most (76-100 women)	Don't know

### Treatments

F4. For most women with early stage breast cancer, how much would waiting 4 weeks after diagnosis to make a treatment decision affect their chance of survival?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	A little bit	Somewhat	Quite a bit	A lot	Don't know

	Yes	No	Don't know
F5. Can breast cancer cells be present in other parts of the body even if the surgeon removes all of the tumor from the breast?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F6. Can breast reconstruction be done immediately after mastectomy as part of the same surgery?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F7. Can patients who need radiation after mastectomy ever receive breast reconstruction?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F8. If any breast cancer cells are found under the arm, do <u>all</u> lymph nodes under the arm need to be removed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F9. Does removing all the lymph nodes under your arm increase the risk of arm swelling?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

F10. After which surgery is it more likely that women will need to have another operation to remove more breast tissue?

- ☐ Lumpectomy
- ☐ Mastectomy
- ☐ There is no difference between these two treatment options
- ☐ Don't know

F11. Which treatment gives women a better chance of surviving breast cancer?

- ☐ Lumpectomy with radiation
- ☐ Mastectomy
- ☐ There is no difference between these two treatment options
- ☐ Don't know



F12. On average, which treatment results in a higher chance of the cancer coming back anywhere in the body after being treated?

- ☐ Lumpectomy with radiation
- ☐ Mastectomy
- ☐ There is no difference between these two treatment options
- ☐ Don't know

F13. Does removing the “**other**” breast – the breast without cancer – improve survival for ...

	Yes	No	Don't know
a. All women with breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Women with a strong family history of breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Women with a genetic mutation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Women over age 70?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

F14. Does removing the “**other**” breast – the breast without cancer – prevent the cancer from coming back for ...

	Yes	No	Don't know
a. All women with breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Women with a strong family history of breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Women with a genetic mutation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Women over age 70?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Partial breast irradiation, sometimes called PBI, involves treating only the part of the breast where the tumor was found – instead of the whole breast.

F15. Before today, had you ever heard of partial breast irradiation (PBI)?

<input type="radio"/>	<input type="radio"/>
Yes	No

F16. Compared to women who get whole breast irradiation, do women who get partial breast irradiation (PBI) ...

	Yes	No	Don't know
a. Have the same chance of the cancer coming back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Have fewer radiation treatments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Have fewer side effects?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Have better cosmetic appearance of the breast?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section G: Communicating with Your Doctors

	None of the time	A little of the time	Some of the time	Quite a bit of the time	All of the time
G1. When it came to getting treatment for breast cancer, I preferred to be told what to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G2. When it came to getting treatment for breast cancer, I wanted <u>my doctor</u> to tell me what to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G3. I preferred to make my <u>own</u> decisions about my treatments for breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

G4. For the next set of questions, please think about the surgeon who was most involved in your surgery.

I feel that my surgeon...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Provided me with choices and options for my breast cancer treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Understood how I saw things with respect to my breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Expressed confidence in my ability to make decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Listened to how I would like to handle my breast cancer treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Encouraged me to ask questions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Tried to understand how I saw things before offering an opinion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

G5. These next questions are about the medical oncologist who was most involved in the decision about whether or not you had or plan to have chemotherapy.

**If you did not see a medical oncologist,  
please go to G6 below**

I feel that my medical oncologist...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Provided me with choices and options for my breast cancer treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Understood how I saw things with respect to my breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Expressed confidence in my ability to make decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Listened to how I would like to handle my breast cancer treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Encouraged me to ask questions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Tried to understand how I saw things before offering an opinion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

G6. These next questions are about your primary care provider - the health care provider that you see for general illnesses or routine checkups.

How long have you been seeing your current primary care provider?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Less than 6 months	6 months to 11 months	1 year to 2 years	More than 2 years

G7. Please read each statement and **mark ONE response on each row.**

	Never	Rarely	Sometimes	Often	Always
a. When you have a new health problem, do you go to your primary care provider before going somewhere else?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. When the office is open and you get sick, would someone from there see you the same day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. When the office is open, can you get advice quickly over the phone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Often	Always
d. When the office is closed, is there a phone number you can call when you get sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. When you go to see your primary care provider, do you see the same provider each time?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Does your primary care provider know what problems are most important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. After going to the specialist or special service for breast cancer, did your primary care provider talk with you about what happened at the visit?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

G8. How much did your primary care provider participate in your breast cancer treatment decisions?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	A little bit	Somewhat	Quite a bit	A lot

G9. **In the past 6 months**, how often did your primary care provider seem informed and up-to-date about the care you got from your breast cancer doctors?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Always

## Section H: Methods of Communication

H1. **Since you were diagnosed with breast cancer**, how often have you used these methods of communication to discuss your breast cancer diagnosis, your treatment decisions, or the care you have received?

	Never	Rarely	Sometimes	Often	Very often
a. E-mail or texting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Social media such as Facebook, Twitter, or blogs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Web-based support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H2. Did you use email or texting, social media (such as Facebook, Twitter, or blogs), or web-based support groups to do any of the following things? **Please mark ALL that apply on each line.**

	Email or texting	Social media	Web-based support groups	None of these
a. Letting people know you had breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Getting opinions or advice about treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Deciding which doctors you wanted to treat your breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Sharing opinions about doctors you saw for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Dealing with negative feelings and emotions about breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section I: Your Thoughts and Feelings

The questions below are important to help us better understand how women like you feel towards the end of treatment and the beginning of the recovery period. Please answer these questions the best way you can.

I1. How likely do you think it is that your breast cancer will come back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all likely	A little likely	Somewhat likely	Quite likely	Very likely

I2. For the question below, please write in a number from 0% to 100% where...

0% = you think there is absolutely no chance that your breast cancer will come back in the breast or the area around it in the next 10 years, and

100% = you think it is absolutely certain that your breast cancer will come back in the breast or the area around it in the next 10 years

After receiving all the planned treatments, what do you think is the chance that your cancer will come back in the breast or the area around it within 10 years?

\_\_\_\_\_ % (0 to 100)

I3. After receiving all of the planned treatments, do you consider your risk of the cancer coming back in the breast or the area around it to be:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very low	Low	Moderate	High	Very high

14. Next, we would like to ask you for your opinion on the chances of your cancer spreading to other parts of your body. For the question below, please write in a number from 0% to 100% where...

0% = you think there is absolutely no chance that your breast cancer will spread to other parts of your body in the next 10 years, and

100% = you think it is absolutely certain that your breast cancer will spread to other parts of your body in the next 10 years

After receiving all the planned treatments, what do you think is the chance that your cancer will spread to other parts of your body within 10 years?

\_\_\_\_\_ % (0 to 100)

15. After receiving all the planned treatments, do you consider your risk of the cancer spreading to other parts of your body to be:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very low	Low	Moderate	High	Very high

16. In your case, how effective do you think chemotherapy is in reducing the chance of cancer coming back in other parts of the body?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all effective	A little effective	Somewhat effective	Quite effective	Very effective

17. **In the past month**, how often have you worried about your cancer coming back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Almost never	Rarely	Sometimes	Often	Almost always

18. **During the past month**, how often has worrying about your cancer coming back...

	Almost never	Rarely	Sometimes	Often	Almost always
a. Made you feel upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Made it difficult for you to carry out your usual daily activities at home or at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Made you feel distant from family and friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section J – Family History of Cancer

To help us better understand your family history, please answer the following question to tell us if any of your blood relatives have had breast cancer and how old they were at the time of their breast cancer diagnosis.

J1. Has your mother ever been diagnosed with breast cancer?

- ☐ Yes, my mother was diagnosed with breast cancer before age 50.
- ☐ Yes, my mother was diagnosed with breast cancer at or after age 50.
- ☐ No
- ☐ Don't know

### Sisters

J2. How many sisters do you have? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

J3. How many of your sisters have been diagnosed with breast cancer? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

J4. Have any of your sisters been diagnosed with breast cancer before age 50? ☐ Yes ☐ No ☐ Don't know

### Daughters

J5. How many daughters do you have? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

J6. How many of your daughters have been diagnosed with breast cancer? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

J7. Have any of your daughters been diagnosed with breast cancer before age 50? ☐ Yes ☐ No ☐ Don't know

J8. Although it is uncommon, men can also get breast cancer. Has a man in your family (blood relative) ever been diagnosed with breast cancer?

- |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Yes                   | No                    | Don't know            |

J9. Have any of your parents, brothers, sisters, or biological (blood related) children ever been diagnosed with any of the cancers below? **Please mark ALL that apply.**

- |   |                                      |                                       |   |   |
|---|--------------------------------------|---------------------------------------|---|---|
| <input type="radio"/> Ovarian cancer    | <input type="radio"/> Uterine cancer | <input type="radio"/> Prostate cancer | <input type="radio"/> Colon cancer          | <input type="radio"/> Stomach (gastric) cancer  |
| <input type="radio"/> Pancreatic cancer | <input type="radio"/> Brain cancer   | <input type="radio"/> Sarcoma         | <input type="radio"/> Ocular melanoma (eye) | <input type="radio"/> Cutaneous melanoma (skin) |

J10. Has your spouse or partner ever been diagnosed with any type of cancer?

- |                       |                       |                                  |
|-----------------------|-----------------------|----------------------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/>            |
| Yes                   | No                    | I don't have a spouse or partner |

## Section K: Home and Work

K1. Before you were diagnosed with breast cancer, did you work for pay?

☐  
Yes

☐  
No

K2. Before you were diagnosed with breast cancer, what was your employment status?

Please mark **ALL** that apply.

☐ Employed full-time

☐ Retired

☐ Employed part-time

☐ Student

☐ Unemployed and looking for work

☐ Homemaker

☐ Temporarily laid off or on sick or other leave

☐ Other (please explain): \_\_\_\_\_

☐ Disabled

\_\_\_\_\_

K3. On average, about how many hours per week did you work before your diagnosis? \_\_\_\_\_ hours per week

K4. At the time of your breast cancer diagnosis, which of the following was available to you through your employer? Please mark **ALL** that apply.

☐ I did not work for pay at the time of my diagnosis with breast cancer

☐ Paid sick leave

☐ Disability benefits

☐ Flexible work schedule

☐ None of the above

☐ Other (please explain): \_\_\_\_\_

K5. At the time of your breast cancer diagnosis, what was the total yearly income of your entire household, before taxes, from all sources – including child support, alimony, disability, social security, and unemployment?

☐ Less than \$5,000

☐ \$40,000-\$59,999

☐ \$5,000-\$9,999

☐ \$60,000-\$89,999

☐ \$10,000-\$19,999

☐ \$90,000 or more

☐ \$20,000-\$29,999

☐ Don't know

☐ \$30,000-\$39,999



K6. **At the time of your breast cancer diagnosis**, how many people were supported by the total income for your household, including yourself?

- ☐ 1 (just you)      ☐ 2 people      ☐ 3 people      ☐ 4 or more people

K7. Did you work for pay during any of your breast cancer treatment?

- ☐ Yes      ☐ No

K8. Are you currently working for pay?

- ☐ Yes      ☐ No

K9. Which of the following best describes your current employment status? **Please mark ALL that apply.**

- ☐ Employed full-time      ☐ Retired  
☐ Employed part-time      ☐ Student  
☐ Unemployed and looking for work      ☐ Homemaker  
☐ Temporarily laid off or on sick or other leave      ☐ Other (please explain): \_\_\_\_\_  
☐ Disabled      \_\_\_\_\_

K10. What type of medical insurance do you have now? **Please mark ALL that apply.**

- ☐ None  
☐ Insurance provided through my current or former employer or union (including HMO)  
☐ Insurance provided to another family member (e.g., spouse) through their current or former employer or union (including HMO)  
☐ Insurance purchased directly from an insurance company (by you or another family member)  
☐ Medicaid (Medi-Cal) or other state provided insurance  
☐ Medicare/government insurance  
☐ TRICARE or other military health care  
☐ VA (including those who have ever used or enrolled for VA health care)  
☐ Indian Health Service  
☐ Other (please explain): \_\_\_\_\_

## Section L: Language Preferences

L1. What language do you primarily speak? **Please mark ONE.**

- ☐ English      ☐ Mandarin      ☐ Cantonese      ☐ Korean  
☐ Spanish      ☐ Vietnamese      ☐ Japanese      ☐ Other (please explain): \_\_\_\_\_

L2. In general, what language(s) do you read and speak?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	English better than any other language	Both equally	Another language better than English	Only another language

L3. What language do you usually speak at home?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	More English than any other language	Both equally	Another language more than English	Only another language

L4. In what language do you usually think?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	More English than any other language	Both equally	Another language more than English	Only another language

L5. What language do you usually speak with your friends?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	More English than any other language	Both equally	Another language more than English	Only another language

## Section M: A Few More Questions

M1. Today's date is: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
                                  month      day      year

M2. How often do you have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Always

M3. How often do you find numerical information to be useful?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Very often

M4. About how tall are you? \_\_\_\_\_feet \_\_\_\_\_inches or \_\_\_\_\_meters

M5. **At the time of your breast cancer diagnosis**, about how much did you weigh?

\_\_\_\_\_pounds or \_\_\_\_\_kilograms

M6. **Before your breast surgery**, what was your bra cup size?

- ☐ A ☐ D  
☐ B ☐ DD  
☐ C ☐ Other (please explain): \_\_\_\_\_

M7. **In the 12 months before your diagnosis with breast cancer**, what was your experience with your menstrual periods?

- ☐ I had no menstrual periods in the 12 months before my breast cancer diagnosis  
☐ I had regular (or the usual timing of) menstrual periods in the 12 months before my breast cancer diagnosis  
☐ I had a change in the timing of menstrual periods in the 12 months before my breast cancer diagnosis

M8. **In the 12 months before your breast cancer diagnosis**, did you experience hot flashes or night sweats at any time – even once?

- ☐ Yes ☐ No

M9. What is your birth date? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
month day year

M10. **When you were diagnosed with breast cancer**, what was your marital status?

- ☐ Married ☐ Living with partner  
☐ Divorced ☐ Widowed  
☐ Separated ☐ Never married

M11. What is the highest level of education you have completed?

- ☐ No high school ☐ Some college or technical school  
☐ Some high school ☐ College graduate (Bachelor's degree)  
☐ High school graduate or G.E.D. ☐ Graduate degree or higher

M12. Are you of Hispanic, Latino, or Spanish origin?

- ☐ Yes, Mexican, Mexican-American, or Chicano
- ☐ Yes, Puerto Rican
- ☐ Yes, Cuban
- ☐ Yes, another Hispanic, Latino, or Spanish origin (please explain): \_\_\_\_\_
- ☐ No

M13. Are you of Ashkenazi (Eastern European) Jewish descent?

<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Don't know
------------------------------	-----------------------------	-------------------------------------

M14. For how many years have you lived in the United States? \_\_\_\_\_ years

M15. In what country were you born? \_\_\_\_\_

☐ Don't know

M16. In what country was your mother born? \_\_\_\_\_

☐ Don't know

M17. In what country was your father born? \_\_\_\_\_

☐ Don't know

M18. Which of the following best describes your race? **Please mark ALL that apply.**

- ☐ White
- ☐ Black or African-American
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Asian Indian
- ☐ Other Asian (please explain): \_\_\_\_\_
- ☐ Other Race (please explain): \_\_\_\_\_
- ☐ Chinese
- ☐ Filipino
- ☐ Japanese
- ☐ Korean
- ☐ Vietnamese

## Section N: Your Doctors

N1. We want to learn from doctors about better ways to communicate with patients and their families about treatment decisions. The information you provide below will help us contact the doctors who treat patients like you. The doctors may be surveyed about their treatment practices. Importantly, your answers will not be shared with any doctors and your personal information including your name will not be used in any communication.

a. **Surgeon** who performed your first lumpectomy or mastectomy:

Doctor's last name: \_\_\_\_\_

Doctor's first name: \_\_\_\_\_

Name of hospital or clinic: \_\_\_\_\_

City: \_\_\_\_\_

b. **Medical oncologist** who talked to you about or delivered chemotherapy or hormonal therapy:

Doctor's last name: \_\_\_\_\_

Doctor's first name: \_\_\_\_\_

Name of hospital or clinic: \_\_\_\_\_

City: \_\_\_\_\_

c. **Radiation oncologist** who talked to you about or delivered radiation therapy:

Doctor's last name: \_\_\_\_\_

Doctor's first name: \_\_\_\_\_

Name of hospital or clinic: \_\_\_\_\_

City: \_\_\_\_\_

d. **Plastic surgeon or breast surgeon** who performed your breast reconstruction:

Doctor's last name: \_\_\_\_\_

Doctor's first name: \_\_\_\_\_

Name of hospital or clinic: \_\_\_\_\_

City: \_\_\_\_\_

e. **Primary Care Provider** (or family doctor) who sees you for general illnesses or routine checkups:

Doctor's last name: \_\_\_\_\_

Doctor's first name: \_\_\_\_\_

Name of hospital or clinic: \_\_\_\_\_

City: \_\_\_\_\_

Please continue to the next page

N2. How can we do better? Did we miss anything in this survey that was important to the experience of making breast cancer treatment decisions? Please tell us about it below.

**Remember, your responses are confidential and will not be shared with your doctors.**

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

**Thank you very much for filling out this survey! Your answers are very important to us.**